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**TITLE:** Seeing is believing: healthcare professionals' perceptions of a complex intervention to improve care towards the end of life – a qualitative interview study.

**SHORT TITLE:** Complex interventions and end of life care

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## **KEY STATEMENTS**

### **WHAT IS ALREADY KNOWN ABOUT THIS TOPIC?**

Complex interventions, aimed at improving the care of patients who may be approaching the end of life, have become increasingly common.

Healthcare professionals' experiences in using them are poorly understood.

### **WHAT THIS PAPER ADDS**

The complex intervention we examine (the AMBER care bundle) is regarded variously by healthcare professionals as: a means of labelling or categorising patients; a tool to change care delivery; and serving a symbolic purpose to influence the behaviours of individuals and teams.

Adequate experience of using the complex intervention, alongside routine care, is necessary in order for healthcare professionals to see the potential benefit.

Infrastructure to support training can be variable, and therefore fidelity and inconsistency in the delivery of the complex interventions remain a concern.

### **IMPLICATIONS FOR PRACTICE**

The perceived purpose of complex interventions can affect how healthcare professionals engage with them.

Understanding potential differing interpretations is essential to optimise training and education, and ensure implementation is consistent and successful.

## **ABSTRACT** (246 words)

**Background:** Methods to improve care, trust and communication are important in acute hospitals. Complex interventions aimed at improving care of patients approaching the end of life are increasingly common. Whilst evaluating outcomes of complex interventions is essential, exploring healthcare professionals' perceptions is also required to understand how they are interpreted; this can inform training, education and implementation strategies to ensure fidelity and consistency in use.

**Aim:** To explore healthcare professionals' perceptions of using a complex intervention (AMBER care bundle) to improve care for people approaching the end of life, and their understandings of its purpose within clinical practice.

**Design:** Qualitative study of healthcare professionals. Analysis informed by Medical Research Council (MRC) guidance for process evaluations.

**Setting/participants:** 20 healthcare professionals (12 nursing, 8 medical) interviewed from three London tertiary National Health Service hospitals. Healthcare professionals recruited from palliative care, oncology, stroke, health and aging, medicine, neurology, and renal/endocrine services.

**Results:** Three views emerged regarding the purpose of a complex intervention towards the end of life: labelling/categorising patients; tool to change care delivery; serving symbolic purpose indirectly affecting behaviours of individuals and teams. All impact upon potential utility of the intervention. Participants described the importance of training and education alongside implementation of the intervention. However, adequate exposure to the intervention was essential to witness its potential added value, or embed it into practice.

**Conclusions:** Understanding differing interpretations of complex interventions essential. Consideration of ward composition, casemix, and potential exposure to the intervention is critical for their successful implementation.

## INTRODUCTION

Methods to improve care, promote trust and improve communication have never been more important in acute hospitals. In recent years, hospital care has been criticised for an absence of open and honest discussions with patients and families<sup>1 2</sup> guided by skilled and confident healthcare professionals<sup>1, 3, 4</sup>. In England and Wales only 25-42% of deaths are unexpected<sup>5</sup>, and in a recent cohort study in Scotland 29% of patients had died within a year of an admission to hospital<sup>6</sup>. In the UK, initiatives have been developed to address inadequacies in communication, and encourage the proactive identification of those who may be in their last year of life to facilitate exploration of their needs, preferences and priorities<sup>7</sup>.

Many tools that seek to influence healthcare behaviours or delivery, or improve health related outcomes for service users, could be described as complex interventions<sup>8</sup>. These interventions often have a number of interacting components, and no clear linear causal pathway linking them to outcomes (mechanism of action). The complexity often arises from the need to influence multiple individuals, systems and services.

In recent years complex interventions<sup>8, 9</sup> aimed at improving the care of patients who may be approaching the end of life have become more common. A number of these interventions have sought to systematise care delivery, delineating recommended actions, and encouraging clear documentation of decisions and discussions with patients and their families. Some such interventions, including the *'Liverpool Care Pathway for the Dying Patient'* (LCP), have lacked vital comparative evaluation to examine their potential benefits or harms early in their use<sup>10</sup>. The LCP, developed in the 1990s, was seen as a way of transferring elements of practice from hospice settings into acute hospitals. However, experiences of poor care attributed to the use of the LCP, as well as a lack of evidence to support its use, resulted in an independent review<sup>3</sup> and its subsequent withdrawal<sup>10</sup>. This failure to transfer a complex intervention from one setting to another, highlights the importance of a thorough assessment of implementation needs, including consideration of:

intervention components; individual professionals involved; the inner setting (institution); the outer setting (healthcare service and current political climate); as well as implementation processes, such as training, education and infrastructure<sup>11</sup>.

In 2010, The AMBER care bundle was developed to improve care in the acute hospital setting for those patients who are: deteriorating; clinically unstable; with limited reversibility; and at risk of dying in the next one to two months<sup>12</sup>. This algorithmic intervention was designed to encourage healthcare professionals to work with patients and families to develop and document a clear medical plan, including consideration of anticipated outcomes, cardiopulmonary resuscitation and escalation status. This plan is revisited daily. The AMBER care bundle encourages regular communication with the patient and family, regarding treatment plans, place of care and any other concerns (see online appendix). It was designed to work alongside active medical care when there remains uncertainty about outcome. A recent comparative study of the AMBER care bundle revealed a mixed picture; whilst it was associated with increased frequency of discussions about prognosis between clinicians and patients, and higher awareness of their prognosis by patients, clarity of information was rated lower than the comparison group<sup>13</sup>.

It is widely acknowledged that evaluation of complex interventions focusing on patient-centred outcomes is vital<sup>14,15</sup>. However, in order for an intervention to be successfully implemented, it is critical that healthcare professionals' experiences are also examined to understand: how interventions are interpreted; the perceived impact of the intervention; and the significance of the specific context to implementation and use. This knowledge in turn can inform training and education, and implementation strategies to ensure fidelity and consistency in use. The challenges for healthcare professionals of delivering care towards the end of life have previously been described, as have the generic issues associated with implementation of complex interventions. However, the experiences where these two contexts overlap (complex interventions used towards the end of life) have received less attention.

The aim of this study was to examine healthcare professionals' perceptions of using a complex intervention to improve care for people approaching the end of life, and their understandings of its purpose within clinical practice. The timing of our comparative evaluation (in 2013 alongside the heightened sensitivity around end-of-life care and the withdrawal of the LCP) provided an opportunity to utilise the AMBER care bundle as a lens through which to explore more broadly healthcare professionals' experiences and interpretations of, and attitudes towards, complex interventions.

## **METHODS**

### ***Design***

Qualitative study with in-depth semi-structured interviews with healthcare professionals.

### ***Setting***

Three large UK acute tertiary NHS hospitals. In two of the three hospitals the AMBER care bundle was implemented on all wards. In the third hospital, a stepwise implementation was being piloted, with implementation across five wards. Healthcare professionals were recruited from palliative care, oncology, stroke, health and aging, medicine, neurology, and renal/endocrine services across the three hospitals. These services were selected as they were either utilising the AMBER care bundle to support the care of their patients, or had a patient casemix where utilisation of the AMBER care bundle would be appropriate.

### ***Governance***

Ethical and research governance approvals were obtained (London Dulwich NRES - Ref: 12/LO/0043) and all procedures followed were in accordance with Declaration of Helsinki.

## ***Sampling***

Healthcare professionals with experience of utilising the AMBER care bundle in practice were recruited to the study. As the decision to support the care of an individual using the AMBER care bundle is jointly made between the nursing and medical staff, recruitment was limited to these professionals. To further examine experiences of delivering care to people who are clinically unstable, staff were also interviewed who worked within services where the AMBER care bundle intervention could be appropriate given the patient casemix, but was not currently implemented. This enabled examination of the potential utility of the AMBER care bundle within these services, or potential barriers to implementation, as well as experiences of other interventions including the LCP. Therefore healthcare professionals were purposively sampled by:

- Exposure to a complex intervention to improve care delivery for those who may be approaching the end of life (the AMBER care bundle)
- Profession (nurse/doctor)
- Seniority (junior/senior: senior doctors were those at registrar and consultant level (specialty doctors, and firm leads), and junior doctors were foundation doctors and core trainees who had not yet commenced their specialisation. Junior nurses were staff nurses (first nursing grade after qualification), senior nurses were ward sisters, matrons and nurse consultants).

Inclusion criteria: nursing and medical healthcare professionals delivering inpatient care to adults who are clinically unstable, deteriorating, with limited reversibility and at risk of dying in the next 1-2 months.

Exclusion criteria: nursing and medical healthcare professionals delivering care in outpatients services only, to children, or to adults who are not clinically unstable; and other allied health professionals.



### ***Recruitment of potential sample***

Potential participants were informed about the study by posters displayed in the staff ward areas and encouraged to contact the researcher (KB) to organise a convenient time to be interviewed. Participants were recruited between February and August 2013 and gave informed consent before the interview with the researcher (KB), a sociolinguist with extensive interviewing experience. All participants were interviewed in a location of their choosing, either a meeting room near the ward on which they worked, or at the researcher's office. All interviews were undertaken face-to-face with no additional persons present.

### ***The interviews***

The topic guide was developed by the multi-professional project steering group and informed by a review of the literature around healthcare professional experiences of complex interventions (see online appendix 2). The interviews aimed to explore participants' experiences of delivering care to people who may be approaching the end of life. For those with experience of using the AMBER care bundle intervention, interviews explored in detail their experience of using the complex intervention, and their views of its impact on care delivery. All interviews were digitally audio-recorded and transcribed verbatim. Recruitment continued until data saturation was achieved.

### ***Analysis***

Interviews were analyzed (by KB and JK) using inductive thematic analysis<sup>16</sup>. This involved five stages: familiarisation, coding, theme development, defining themes, and reporting. Coding was facilitated using N-Vivo qualitative data analysis software (Version 10). Further interpretive analysis was undertaken informed by the Medical Research Council (MRC) guidance for process evaluations, focusing on: context; implementation of the intervention; and

mechanism of impact, with additional consideration of the interpretation and perceived purpose of the intervention.

To maximise analytical rigour, a re-iterant process of discussing areas of agreement and disagreement took place between KB, and JK to achieve consensus. Alternative interpretations were incorporated in the analysis. The analysis was further tested during discussions with colleagues and meetings of the project steering group. Attention was also paid to non-confirmatory cases where emerging themes contradicted more common idea<sup>17</sup>.

## **RESULTS**

### ***Participants***

Twenty interviews were conducted with healthcare professionals (see table 1). Twelve were recruited from wards where the complex intervention (the AMBER care bundle) had been implemented, and eight from wards that continued to deliver usual care. Participants comprised: six junior nurses; six senior nurses; four junior doctors; and four senior doctors. Of note, although not strictly a nursing healthcare professional, one student nurse and one healthcare assistant were also included in the nursing sample as they were keen to participate in the study; they have been categorised within the junior nursing sample. Fifteen participants were women, and interviews had a median duration of 29 minutes (range 11-45).

*(Insert table 1 here)*

## **Findings**

Two broad themes emerged from the interviews pertaining to: (1) the purpose, or perceived mechanism of effect, of a complex intervention to improve care towards the end-of-life; and (2) implementation of the intervention.

### **i. Perceived purpose of the intervention**

Participants described their experiences of utilising the complex intervention in care delivery. From these descriptions, three purposes for the intervention emerged: (i) a label, as a means of categorising patients; (ii) a tool as a means of directly changing the way care is delivered; and (iii) serving a symbolic purpose, indirectly altering individual and team behaviours.

#### **a. Label**

Through their experiences, participants described the use of the complex intervention as a means of labelling or categorising patients. This passive allocation of a label however was associated with different consequences. For some, particularly the senior medical staff, the purpose of the labelling provided a shortcut to communication.

*'Once it had been implemented, really embedding it so that, if a person is on AMBER there is an AMBER coloured 'A' by the patient's name on the board so everyone knows that person's AMBER, and on the daily ward round where the patient is discussed it's this is Mrs Bloggs this is an AMBER patient in the same way as this is Mrs Bloggs she's got heart disease. AMBER is up there straight away' 20:SD4*

The integration of the intervention into everyday ward practices enabled senior clinicians to use the label to deliver clear, concise efficient information within the care team, removing the potential for ambiguity or misinterpretation.

*'A coherency across the board and everyone who's looking after them being aware that the situation has changed or is acute or there is an issue with the patient. And everyone across the board knows, there's something critical going*

*on or, serious going on that in that way I think it's a really clear mark to everyone.'* 19:SD3

For senior medical staff, this labelling had a positive association, with improved situational awareness amongst the whole care team; a means of efficiently and effectively disseminating information.

*'I think it helps that common watch word of AMBER. Everyone knows the same things almost like, in a sports analogy, let's say you were a rugby team they've got their coder at the line out they throw the ball in. There's a word, everyone knows what's going on.'* 20:SD4

In addition, this improved awareness encouraged a renewed focus on the goals of care for the patient. This in turn was also associated with improved awareness of the clinical situation for relatives also. One nurse in viewed the complex intervention as a means of reducing the potential communication gap between healthcare teams and patients and family.

*'As soon as we highlight that maybe this patient should be on AMBER it then alerts other people to say maybe we should be gearing them up to actually get to where they want to be rather than just trying to keep them in hospital for multiples of tests that aren't necessary. It also alerts their relatives as well, what the actual position that they should be in and what they should start thinking about.'* 11:JN6

However, others described negative connotations associated with using the complex intervention as a label. Nursing staff in particular described that labelling, or categorisation, could be mistakenly associated with containment, or limiting of care options, particularly for those less familiar with the intervention.

*'With regards to decision making, that's usually made prior to the AMBER care bundle, and that's what we're trying to change at the moment. I'm finding that, I*

*said “What about the AMBER care bundle for this patient” he said “No, we want to do all the investigations first” and I think, that patient can still have their care supported with the AMBER care bundle, and then you can carry on doing all your investigations.’ 15:SN6*

This has particular implications towards the end of life where reduction or withdrawal of treatments must be handled with extreme sensitivity. Indeed, one nurse described shying away from any form of labelling for fear of how patients and families would respond.

*‘You do have the discussion with them about what’s going on, how poorly the patient is and is likely to deteriorate but you haven’t said “Oh, we’re going to put them on AMBER care bundle” because there’s going to be “What what’s AMBER like LCP?”’ 9:JN4*

Such concerns around labelling were heightened against the backdrop of negative media attention at the time of the study surrounding the withdrawal of the *‘Liverpool Care Pathway for the Dying Patient’*.

#### **b. Tool**

Participants also described using the complex intervention as a tool to actively alter the manner in which care was delivered. For some, the main purpose of the tool was to serve as a prompt to ensure that critical conversations were carried out with patients and families and to increase the frequency of communication more generally. These views were more common amongst nursing and junior medical, rather than senior medical staff.

*‘The communication is much improved with the AMBER bundle. I don’t think we should have an EPR flag that tells us we have to speak to relatives everyday but you know for this sensitive group of patients, that, you know we do need to speak to the family speak to the patients a little bit more about how they’re doing on a daily basis it can’t be a bad thing.’ 14:SN5*

However, negative reactions to the complex intervention as a prompt were also identified. Participants described colleagues questioning the need for an intervention, believing that it somehow undermined their clinical skills and intuition. For these individuals there was not a clear sense of why the intervention was required, and what it delivered above and beyond standard care.

*'There's other people who almost treat it as an affront. They sort of think "Well I do that anyway because I'm a good doctor and I talk to my families and I make plans." and they don't like the idea that there has to be a structure a tool for everything and they kind of think "Well I do that".'* 17:JD3

Other participants, who highlighted the importance of evidence of the added value of the intervention, in order to gain support from clinicians, echoed this view.

*'Somehow showing that doing that [using the AMBER care bundle] can be good for their patient and it's going to somehow improve outcomes. So if you had some data to show that actually, you know, preferred place of care was better or family feedback was better or something like that, then maybe they would be willing'*17:JD3

### **c. Symbolic value**

Participants also described the symbolic value of the complex intervention, indirectly affecting individuals and clinical teams. This symbolic value was described primarily by nursing and junior medical staff who identified the intervention as a beacon of 'support', uniting the clinical team. Its use was associated with a 'closer' team, improved team working, and subsequently with 'shared' goals of care for the patient and their family, with clear plans and expectations.

*'I think by using the AMBER bundle as a support mechanism, it's certainly brought us closer together as a team. We certainly have shared goals for the patient and family. There's been no blurring of you know, expectations.'* 14:SN5

However, participants also recognised its impact upon individual team members. The intervention was described as empowering individuals within the team, particularly for the nursing staff.

*'I think that does enhance team working because everyone's on the same page and you're all singing off the same kind of hymn sheet. People feel that they have um a chance to offer their opinion in a way. Gives everyone like a platform to be able to bring their assessment forward for discussion and for the team to kind of reinforce that positively.'* 10:JN5

The intervention performed a symbolic role for these individuals, as a means of legitimising their concerns about a patient's status, and, in so doing, creating a platform to voice those concerns.

Lastly, participants also described the symbolic value of the intervention as a means of demonstrating activity. In a culture of healthcare delivery that measures success on curing and discharging patients, healthcare professionals encounter existential and professional struggles related to delivering high quality care towards the end of life.

*"I do feel like there's a general sense in a lot of wards that if you don't escalate management and you don't try everything that you're somehow giving up on someone...And so there is a feeling that we're...we're failing someone when they die..."* 17:JD3

Participants described the use of the intervention as a means of demonstrating that they were doing all they could to care for the patient. There was a sense, particularly from this junior doctor, that 'active' care was the only accepted method towards the end of life.

## **ii. Implementation of a complex intervention towards the end of life**

Participants also shared experiences regarding the implementation of complex interventions specifically designed to improve care towards the end-of-life. In particular these related to breadth or depth of implementation - hospital wide or ward level – and how ward composition and case mix may impact upon use of the intervention.

### **a. Ward mix / intensive exposure**

Differences in the success of implementation were observed between wards where a high proportion of patients could be appropriate for care supported by the intervention, compared to those with relatively few appropriate patients. Successful implementation was described in settings where dedicated personnel had focused energies in the implementation of the intervention on a small number of wards.

*'Implementation of AMBER does require dedicated personnel in hospitals, and without that it's hard to implement, because there's so many things being thrown at healthcare professionals all the time. Where it was implemented very successfully there were key dedicated personnel implementing it on, um, a small number of hospital areas.'* 20:SD4

Additionally, wards where a high proportion of patients would be eligible for care supported by the intervention also reported positive responses to the implementation.

*'As far as stroke and AMBER is concerned we have for years we have identified these patients. A lot of these aren't you know, receiving active rehab, we also know that for some of the patients death is inevitable. We desperately needed a model if you like, a plan to follow and it wasn't there. So this is why we welcomed AMBER, when it came up.'* 14:SN5

### **b. Ward mix / minimal exposure**

In contrast, on wards where relatively few patients would be appropriate for care supported by the intervention, participants described challenges with implementation due to reduced



familiarity and limited exposure to the intervention. Without adequate acquaintance with the intervention, healthcare professionals may be unlikely to see the potential added value.

*'It's not a regularly used. Well it hasn't been until I got into medicine. If the surgeon came to see one of the medical patients for anything they wouldn't have any idea what this AMBER bundle was all about.'* 16:JD2

In addition, participants described potential 'cultural', or professional, conflicts implementing a complex intervention in wards under the care of multiple specialities. For some specialties, consideration of potential deterioration, and proximity to end of life, is less common.

*'I think it's a combination of the fact that it's a ward that covers three different specialities, but all three of them are so different to each other. I think, again, engaging the neurosurgeons to start thinking about, reversibility are quite slim. Are they going to recover and are they going to die in the next one to two months? I think that will be quite difficult to get some neurosurgeons to actually make that decision.'* 12:SN3

Implementation of a complex intervention to improve care towards the end of life in these mixed wards is associated with 'cultural' challenges outside of the control of the intervention and its associated training and education.

## **DISCUSSION**

This qualitative study identified that healthcare professionals' had differing views regarding the purpose the AMBER care bundle. For some, it served as a means of labelling or categorising patients, almost at an administrative level, whilst for others it served as a tool to change their practice and care delivery. Thirdly, a symbolic value of the intervention was also described, which indirectly affected the behaviours of some individuals and teams.

The perceived purpose of the complex intervention, and associated implications, differed across the participants. Whilst senior medical staff saw the benefits of the complex intervention as a means of labelling or categorising patients, junior medical staff, and nursing staff were more likely to perceive the intervention as a tool, or providing a symbolic value. Specifically, a complex intervention designed to help in the delivery of care for those who may be approaching the end of life, empowered junior and nursing healthcare professionals, giving them confidence and legitimising their concerns. Beyond professional seniority, this finding may also be due to the greater physical time these professionals are exposed to frontline wards where they have more encounters with patients who may be approaching the end of life.

Whilst in the present study this was viewed positively, such symbolic values of interventions have been recognised previously and must be explored carefully to ensure they do not override clinical intuition or distort healthcare professionals' perceptions regarding goals of their care<sup>18</sup>. In addition, further exploration is required to understand why healthcare professionals require, or benefit from, this symbolic value, rather than feeling confident to rely on their clinical experience and intuition.

Participants also shared valuable experiences regarding the implementation of a complex intervention to improve care towards the end of life. In the context of wards where the casemix comprises people under the care of multiple specialties, and where numbers of eligible patients on wards may be relatively low, there is a risk healthcare professionals may not receive adequate exposure to the intervention in order to see the potential added value, and embed it into their clinical practice. Many interventions found to be effective in health services research do not translate into meaningful patient outcomes across multiple contexts<sup>19</sup>. The fidelity, reliability and consistency of complex interventions and how they are interpreted and acted upon is of paramount importance<sup>20, 21</sup>, however fundamental issues around lack of exposure may negate implementation entirely.

## **Limitations**

This study has some limitations. Healthcare professionals were interviewed at a time of their convenience, however often around their busy shifts. On occasion, clinical commitments resulted in participants having a limited time to complete the interview, or, on one occasion, a need to terminate the interview before the close (after 11 minutes). However, each interview provided valuable data, and all core aspects of the topic guide were explored within each interview. Using qualitative methods may limit the generalisability of these results. However, we employed purposive sampling across three large hospitals to ensure diversity among potential participants, both in terms of experience and profession to improve transferability to other settings. A re-iterant process of discussing areas of agreement and disagreement, as well as further discussion with the broader project advisory group was used to ensure rigour in the analysis and interpretation, and to improve credibility, dependability and confirmability of the findings. Further, studies exploring how the perceived purpose of a complex intervention impacts upon individual clinical practice, and optimal levels of exposure to improve implementation of an intervention, are required.

## **CONCLUSION**

This study has important implications for future development and use of complex interventions to improve care towards the end of life. Firstly, the findings from this study demonstrate the importance of 'seeing is believing' - understanding how complex interventions towards the end of life are perceived, interpreted and then acted upon, and by whom, provides important information on appropriate methods of implementation and use. However, differing interpretations of the complex intervention need to be recognised and addressed during training and education to ensure the fidelity and consistency of the intervention across individual patients and different sites<sup>15</sup>. Indeed, the findings from our earlier comparative study<sup>13</sup>, and this exploration of healthcare professional experiences, have informed the design and protocol for a forthcoming feasibility cluster randomised controlled trial of the AMBER care bundle. Secondly, the use of interventions towards the end of life is undoubtedly a politically sensitive area. Importantly, whilst the symbolic values of complex interventions may benefit some healthcare professionals, there is a need to

ensure that the symbolic value does not override or distort clinical intuition<sup>18</sup>. Lastly, this study has also described important considerations specific to implementation of complex interventions towards the end of life. Particular ward composition, case-mix or models of implementation (e.g. without dedicated facilitation for the implementation and sustainability of the intervention) may preclude adequate exposure to the intervention in order to see the potential added value, and embed it into clinical practice.

## **AUTHORS' CONTRIBUTIONS**

JK conceived the design and won funding for this study. KB, JK, IC, WP identified sites and settings for the study. KB conducted the interviews. KB and JK analysed the data. KB and JK drafted the original manuscript with significant input from IJH. All authors contributed to important intellectual revisions and approved the version to be published. JK is guarantor.

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**Table 1: Demographics of Interview Participants**

<b>Seniority / Profession</b>	
Junior Nurse – Standard	3
Senior Nurse – Standard	2
Junior Doctor – Standard	1
Senior Doctor – Standard	2
Junior Nurse – Intervention	3
Senior Nurse – Intervention	4
Junior Doctor – Intervention	3
Senior Doctor - Intervention	2
<b>Specialty</b>	
Medicine	5
Old Age Medicine	4
Old Age / Stroke, Stroke, Stroke / Neurology	3
Oncology	4
Palliative Care	2
Renal / Endocrine	2
<b>Gender</b>	
Female	15
Male	5
<b>Interview Duration (minutes)</b>	
Median	29
Range	11-45